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Participation and the Profoundly Disabled: "Being" Engaged—A Theological Approach

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Thinking about profound disability is being ever deepened by refinements to key principles such as inclusion, friendship, belonging, missing the presence of the disabled person, acceptance, and human rights. This article adds the principle of participation to this thinking. Participation can be understood in two ways: first as joining in*, in which both common understandings and the principles of Catholic Social Teaching demonstrate that participation, especially in liturgical practice, goes beyond notions of citizenship or the requirements of justice or rights of people with disabilities. Second, and, more significantly for people with profound disabilities, participation as* being *engaged highlights that the disabled witness to understanding worship as God's work. Moreover liturgy and worship are not only about bringing needs and desires into God's presence: they are about bringing the self.*

KEYWORDS participation, worship, disabled, Vanier, Wojtyła, Pope John Paul II, Levinas, Catholic social teaching

THINKING ABOUT DISABILITY

One of the most powerful shifts in thinking about disability is articulated in the flow from inclusion to belonging to acceptance. Each of these three stages continues to be the subject of exhaustive scrutiny and fine honing. The promise of this reflection is that it fosters a building up of understandings. Jean Vanier, founder of the L'Arche and Faith and Light communities where the abled and disabled share their lives, calls for a path of healing that leads from exclusion to inclusion (Vanier, 1999). Hans Reinders, a pioneer in the

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study of profound disability and inclusion writes extensively of the need to include profoundly disabled people as a matter of choice: to share friendship (Reinders, 2008). John Swinton, a leading writer in disability studies, adds a new dimension to belonging: A sign of belonging is that other people long for your presence so when a person is not there he or she is missed (Henning, 2013). Such a constant defining and redefining demonstrates that the issue of disability strikes deeply and demands careful attention. The more thinking that goes on in disability studies the more profound that thinking becomes. This article seeks to add to that already rich seam of thinking and it takes as its theme the notion of participation.

PARTICIPATION

Participation, from the Latin *partem capere,* meaning *take part*, has a long and complex provenance in philosophy and theology. Certainly participation as *taking part* or *joining in* is important in itself, as is demonstrated by the requirements of inclusion, of belonging, and of acceptance. However, participation has a deeper significance, illustrated by the way in which Christian thinking developed and enriched ancient philosophical notions of participation. Ancient Greek philosophy offered two alternative ways of understanding objective reality. Plato looked to separate and unchanging Ideals, the Forms, and he introduced the notion of participation to explain the relation between "the many" of sensible things and "the One," the Ideal or the Form. According to Plato sensible things participate in separate forms: a chair is a chair because it participates in the form of "the Chair itself." Aristotle looked to changing nature; through his notion of causation, form was bound to matter and participation was made redundant. According to Aristotle's theory, a chair is just the object we are acquainted with in our experience. To overcome this apparent impasse in philosophy efforts were made to reconcile Platonism and Aristotelianism. Neo-Platonists such as Plotinus took participation and linked it to an Aristotelian notion of causality. This resulted in a theory of emanation whereby everything is produced out of the One without a conscious act but as an overflowing in a hierarchy tending downwards to the finite and evil realm of matter. Emanation theory became key in both neo-Platonism and Gnosticism. However this theory did not sit well with Christianity. Christianity had access through Scripture to two central beliefs: that God the Creator personally creates *ex nihilo* and that all human beings are made in God's image and likeness. Theories that denied God's transcendence and his personal creative action as well as Gnostic elitism that allowed for a spark of the divine in only a few enlightened human beings were mistaken. As Clement of Alexandria (c. 202 AD/1983 explains, there are not some "illuminated" Gnostics and some "animal" human beings, for all are equal). Participation in Christian theology then expresses

and safeguards the transcendence of God. It points to the total dependence of all creatures for their very being on the Creator since all substances come to be and continue to be in existence by participation in God. Moreover it indicates that human beings are called to friendship with God, to become "participants of the divine nature" (2 Peter 1:4), as a matter of grace and in a manner suitable for human beings.

Participation then can be seen on at least two levels: first participation as *joining in*, secondly and, more significantly for people with profound disabilities, participation as a connection, *being* engaged or encountered. This is not the same as engaging "being" since here the emphasis is on the one doing the engaging. Instead participation as "being" engaged concentrates on the actual being of the profoundly disabled person in that engagement.

Participation as "Joining In"

Recognizing the importance of participation for people with disabilities fuels much of the work that has been done in disability studies especially in the move towards the social model of disability. This model is often seen as the framework for inclusive participation since it focuses on changing attitudes and removing or minimizing barriers that prevent the disabled from having access to the same opportunities as the abled. Participation is also seen as implicitly behind the drive to involve disabled people in decision-making and in enabling choice. Moreover, participation is seen as a human rights issue. The United Nations *Convention on the Rights of Persons with Disabilities* (2006) recognizes the right to full and effective participation and inclusion of persons with disabilities in political and public life on an equal basis with others. The Human Rights Council asked the Office of the United Nations High Commissioner to consider the issue of participation at the 19th session of the Council. Although the report accepts that participation is widely seen as the right to vote and be elected it also adds that "in its broadest sense, participation is a theme that runs throughout the whole Convention."

Taking participation in its broadest sense and as a matter of a human right the account of participation and the disabled often follows a clearly argued trajectory: Participation is founded on inclusion, belonging, and acceptance. With acceptance comes enabling or empowerment. The first question to ask is, why are people with disabilities excluded? The answer usually recalls the discriminatory practices of seeing the disabled as "users," as "dependant," as "non-productive." Sometimes the notion of fear or discomfort engendered by certain disabled people emerges. Sometimes issues of competitive societies or a "survival of the fittest" mentality are raised. What comes across is that the disabled are an oppressed group and although some progress in the provision of equality and equal opportunities can be

identified not enough has been done. Certainly a level of realism has entered the debate as the actual reality of choices now features as well as recognition that some impairments cannot be overcome simply by removing physical barriers since it is the impairment itself that is a barrier. Nevertheless, merely removing barriers so that the disabled are included is just the first stage. As Hans Reinders (2008) explains, a discussion of rights and justice may help in the removal of barriers. However inclusion, he says, is also a matter of removing the barriers "entrenched in people's hearts and minds": it goes beyond "citizenship to friendship" (p. 6). John Swinton points out that for inclusion a person simply needs to be present; for belonging a person needs to be missed. Although these notions of friendship and "being missed" have a rich and deep significance in their own right they are also ways of overcoming attitudes of fear and unease, or seeing the disabled person merely as non-productive. Understandings of friendship and belonging allow for being accepted, giving a person room. They show that he or she "fits in." When a person has a place then he or she can participate. Of note is that in this trajectory "participate" is understood as "joining in" or "taking part" and enabling this is a matter of justice.

For those who follow the social model of disability and seek to apply it in the realm of Christian religious practice participation perhaps takes on a greater significance. It is not enough that a person is included, that he or she belongs, and that he or she fits in. The structure of Christian religious worship demands that all the baptized take part in the life and mission of the Church. The importance of enabling this taking part is such that barriers must be removed. Just as in the secular realm physical barriers prevent or impede access so too in the sacred realm church architecture, furniture and layout need to be reassessed from leveling steps, ramping, widening doors to choosing contrasting color carefully and providing sound systems and signing. Appropriate language and alternative means of communication, theologically sound yet accessible words in music, need to be thought through. Sacramental programs that are not so exclusively tailored to the intellectually disabled that they add to the person's isolation yet that also address the person's spiritual needs are a pressing priority. An all too common challenge is how to manage the person who appears disruptive or difficult for others, the person who cannot cope with overstimulation or with too many people or with noise or indeed with silence. In addition there is the task of finding those who have been left out for too long, those whose own barriers or the barriers of others prevent them from coming to church whether it be from fear of rejection, embarrassment, previous unhealed experiences or practical difficulties, and inviting them in to what is, after all, home. Certainly there are moves to enable this joining in. Specifically in the United Kingdom after extensive research into the experience of people with intellectual disabilities the *Kairos Forum* was set up in 2013 to offer practical support, specialist advice, and resources so that communities can be fostered and the stories

of people with disabilities can be narrated and accepted. Nevertheless, there remains much to be done.

Participation and Catholic Social Teaching: More Than a Matter Of Justice

In Catholic Social Teaching, participation is a fundamental principle that stands alongside and is intimately linked to other principles. These principles form a unity and they include the option for the poor, human dignity, the common good, subsidiarity, solidarity, and justice. In Scriptural terms, the "poor," in Hebrew *anawim,* embrace all who are needy, lowly, oppressed, forgotten, and overlooked and it includes people with disabilities. One way in which the option for the poor is put into practice is by enabling the participation of disabled people. To be clear, the option for the poor in no way equates to a discriminatory attitude of the kind that is paternalistic or sets up barriers to be overcome nor is it an example of the "strong" doing things for the "weak." It is discriminatory, but in the sense that the option recognizes that the marginalized are those who are particularly loved by God. One of the reasons why they are especially loved by God is because his Son identifies himself with them. Moreover, *anawim* carries the suggestion that these forgotten ones are "bowed down" and as such they demonstrate in their own persons that all depend on God's love and mercy. The call for participation makes explicit the intrinsic dignity that all human beings have regardless of their situation or abilities. Participation adds to the common good, the principle that recognizes the dignity, unity, and equality of all people. The common good belongs to everyone since it acknowledges that the human person cannot find fulfillment in the self since the person exists with and for others, and this applies as much to the abled as the disabled. Participation is a characteristic of subsidiarity, the principle that recognizes that everyone has something original to offer and that others are to help the person where appropriate. Participation is also an expression of solidarity, the principle that highlights that all are responsible for all. Perhaps above all participation is a requirement of justice.

So, on a practical theological level, and on a level that can be appreciated in secular terms, participation as "joining in" and "taking part" is an important advancement in the inclusion, belonging and acceptance trajectory of disability. Indeed it is implicit in these stages. However, participation understood in a more profound sense than "joining in" has an even deeper theological and philosophical significance. This profound sense of participation can take the issue of disability beyond a reflection on what the abled do for the disabled or even what the disabled can achieve on their own. Participation in this sense centers not so much on doing as on being and so it seems especially relevant to the most profoundly disabled people.

Participation: "Being" Engaged and Engaging With Being

An analysis of this deeper theological and philosophical understanding of participation that engages with both the human being as being and his or her activity is offered by Karol Wojtyła, professor of ethics, some years before he became Pope John Paul II. In 1975 Wojtyła presented an insightful paper entitled *Participation or Alienation?* According to Wojtyła (1993/1975), a human being's action fully reveals the person as an "I." For Wojtyła this is significant because it gives priority of being over action: The already existing person (being) is revealed by activity. Participation enters the discussion because this revelation of the person takes place through participation. It occurs through an encounter with another, an engagement. In one regard, participation necessarily involves the awareness of the other as another "I", and in biblical terms, my neighbor. In another regard, this other, my neighbor, already participates by being present to me. Participation therefore goes both before and beyond empowerment, inclusion, and indeed friendship, belonging, and missing, crucial though these are for an understanding of disability. Undoubtedly empowerment, inclusion, friendship, and belonging and missing have as their focus the one who is empowered, included, befriended, who belongs and is missed. Nevertheless all of these situations seem to rest on the activity of the one who empowers, the one who includes, the one who chooses friendship, the one who makes room and who misses the other when he or she is not there. Participation recognizes that there is an activity of the other at the level of being: In terms of profound disability it is not simply what others do, it is also what the profoundly disabled do for and with others.

Karol Wojtyła and Emmanuel Levinas

This can perhaps be made clearer by exploring a distinction in the thinking of Karol Wojtyła who gives priority to being and the philosopher Emmanuel Levinas who gives priority to ethics. Levinas was much admired by Wojtyła and they both share similar concerns. Indeed it is useful to consider their different starting points as offering complimentary reflections. Both recognize that understanding the other in terms of what he or she has in common with other beings tends towards making the other the same. This is a reduction of the other and it risks turning the relationship into one of power over the other. What both Levinas and Wojtyła wish to convey is that the "I" and the "other I" can enter into relation with each other without destroying the separation of each of us. Wojtyła achieves this by his focus on the uniqueness of each human being. Levinas achieves this by his emphasis on the ethical relation where I exist only in relation to the other yet I am not the other.

However Levinas thinks that it is the priority of being, a priority he takes from the philosophy of Martin Heidegger that allows for seeing the other in terms of similar characteristics and therefore the same. According to Levinas, Heidegger continues the Western tradition of understanding a particular being through knowledge of the universal (Levinas, 1951/1996, p. 5). Levinas rejects the priority of being over the ethical since he is concerned that "being" is too wrapped up in the self and therefore the ego is turned away from the other. Instead Levinas prefers to focus on the concrete actuality of living in the world and interacting with others where the focus is not on "here I am" as a statement of existence. Rather it is on "here I am" as a response to the call of the other. Levinas finds the "other" in this call to responsibility for the other. Moreover this responsibility for the other is pre-rational, it is a spontaneous response to the encounter with the other. As Levinas explains, "I do not only think that he is, I speak to him. He is my *partner* in the heart of a relation which ought only have made him present to me" (emphasis original) (Levinas, 1951 /1996, p. 7). For Levinas then this relation with the other is not ontology (being) rather it is the call of the other, "his invocation" (p. 7). However the focus for Levinas falls on my responsibility, my moral freedom to choose to live out that responsibility for the other. This responsibility does not demand anything from the other in return.

Similarly Wojtyła draws attention to the actual being of the other and not to some universal idea of the human being. According to Wojtyła the spontaneous awareness that the other is an other is not gained through the knowledge that the two share humanity. It is not a matter of characteristics or of a universal concept. Rather, like Levinas, the relationship is always "interhuman" (Wojtyła, 1993/1975, p. 201), it is an experience of the other. However Wojtyła thinks it is important to recognize the truth that the other is unique and unrepeatable, a truth that is found in being rather than obscured by it and in this sense Wojtyła's understanding of "being" differs considerably from Heidegger's. Of course it could be argued that by saying each human being is unique one is merely admitting that all human beings are the same: Each one of us is special so in fact no one is special. However that is to overlook the significance identified by early Christian thinkers like Gregory of Nyssa that each human being is like a new world in the created world, each has his or her own perspective on the world that cannot be repeated by any other human being (c. 380 1972/XVI). When that person dies so too does his or her unique and unrepeatable perspective. Moreover the truth that each person is special and that this is a meaningful truth is borne out in family relationships: for many parents each of their children really is special and this cannot be reduced to seeing their children as the same. More significantly, in theological terms the acknowledgment that each is uniquely made in the image of God, that each is another Christ defies reduction. As Tertullian (c. 208/1995) explains about human beings, "in whatever way the

clay was pressed out" God "was thinking of Christ, the Man who was one day to be: because the Word, too, was to be both clay and flesh" (6; Second Vatican Council, 1963/1992a, #22).

For Wojtyła the focus on the truth of the unique being of the other means that in encounter the other is seen as a whole and I am seen as a whole: this engagement is not complimentary in the sense that encounter makes me whole. Rather the wholeness of the other compliments my own wholeness. This is the basis for the solitude and *communio* that forms such as essential part in Wojtyła's *Theology of the Body* written when he became Pope.

The significance of these distinctions for people with disabilities requires perhaps further teasing out. Thinking of profoundly disabled people as the same as the abled, considering what we all share in common and in particular focusing on our common humanity and so pursuing equal opportunities and access is laudable. We all belong to one human family. Nevertheless, this risks entering into relationships characterized by power or unrealistic expectations. Thinking of profoundly disabled people in terms of encounter where the abled are summoned to responsibility for the other is a requirement of justice. Nevertheless, this risks becoming one-sided such that people with profound disabilities remain passive receivers. In its extreme it risks seeing the disabled as objects of kindness or thoughtfulness. In both cases attention is on the activity of just one of the parties. However, where Levinas is concerned about acting *for* others, Wojtyła reminds us that it is about acting *with* others. In terms of profound disability this is an important distinction. Responsibility for the other as another "I," particularly the other who is seen to be vulnerable, isolated or marginalized is certainly a loud and demanding call. Nevertheless the recognition that the "other" is not the same as me, a recognition firmly acknowledged by Levinas, is more firmly asserted by Wojtyła who can see that the "other" who is "a whole" also has his or her activity even if this is difficult to grasp by the more active other.

Participation and Theology

Participation also has a further theological dimension. Theologically speaking human beings have been called to share in God's Trinitarian life. Participation in the life of the Trinity is a multilayered rich idea and in part it is expressed by a human being's personal vocation. This personal vocation is an intricate weave where all the different callings are interdependent. So, while each human being is called to holiness, and each human being has a unique vocation, and each human being has a part to play in God's plan of salvation for humanity, these callings interlock. As Pope John Paul explains, every person whatever his or her situation or condition is a worker in God's vineyard. The disabled in particular have both a place and a task in the

building up of the kingdom and for Pope John Paul one of their tasks, "we need you to teach the whole world what love is", is a work of participation that is intimately connected to inclusion and belonging. So he adds "we will do everything we can so that you may find your rightful place in society" (Pope John Paul II, 1988, #53).

Certainly the specific vocation of a profoundly disabled person is perhaps unknown or even unknowable by others and the same may be said for the part each human being has, whether abled or disabled, in God's plan of salvation. As John Henry Newman explains, "God has created me to do Him some definite service; He has committed some work to me which He has not committed to another. I have my mission—I never may know it in this life, but I shall be told it in the next .... I am a link in a chain, a bond of connection between persons" (Newman, 1893/2010). Nevertheless some of the ways in which God has taken up those with disabilities into his plan of salvation have been clearly marked from the calling God made to Moses who was "slow and hesitant of speech" (Exodus 4:11) to Naaman who had a "virulent skin disease" (2 Kings 5:1) to the man born blind (John 9:1–7). So too can something be made of the part played by the profoundly disabled even if this reflects but one aspect of their contribution. Notably, usually it is the abled who think they are doing something for the disabled. Of course action by the abled to include, to ensure belonging, to accept, and to miss the other demonstrates that this is often true. However, what the disabled do for the abled remains unacknowledged possibly because it is not obvious and even more likely invisible. This means that their contribution and participation is overlooked. Certainly Jean Vanier speaks often of people with disabilities who are, as he calls them, "masters at teaching the way of the heart," the way of entering into personal relationships. Indeed Vanier says "people with disabilities have taught me what it means to be human" (Vanier, 1999, pp. 88–93, 97). Still, despite the success of communities like L'Arche Vanier himself recognizes that "liberation of the human heart" is a long and at times painful journey and that those who do enrich our lives are the ones most often excluded (Vanier, 1999, p. 45).

A clear example may help. The commendable and important concern and action of the abled to ensure that the profoundly disabled have access to the sacraments and in particular to join in the liturgy of worship is intended to enable the disabled to take part in the same way as the abled. Hence the focus on making churches accessible, being mindful in church architecture and furnishing, thinking about appropriate liturgy, music, readings. This is undoubtedly a worthwhile endeavor, a matter of justice and concern for all: as Pope John Paul II points out, for "full participation" it is necessary to recognize that "every member of the community has a part to play in the liturgy" (Pope John Paul II, 1998, #3) and it is imperative to make that part possible. Furthermore enabling participation goes beyond a matter of justice: the liturgy is "an 'action' of the *whole Christ*" of the whole community,

the Body of Christ united with its head, Christ (Catechism of the Catholic Church, 1994, #1136, 1140) where all those in the communion are included. Indeed as St Paul points out, "if one part is hurt, all the parts share its pain. And if one part is honored, all the parts share its joy. Now Christ's body is yourselves, each of you with a part to play in the whole" (1 Corinthians 12:26–27). The implication here is that if the disabled are missing from the community then the community is not whole. Moreover, liturgy is a matter of worship, of the proclamation of the Gospel and of active love of others. Enabling others to participate fully is one way in which this active love is demonstrated. However, simply concentrating on enabling the disabled to do as far as is possible what others do risks overlooking their own rather specific contribution.

One aspect of this contribution can come to the fore once it is remembered that there is also a personal aspect to liturgy as well as a communal one. As the Second Vatican Council's document on the Sacred Liturgy explains, liturgical services "touch individual members of the Church in different ways, depending on their orders, their role in the liturgical services, and their actual participation in them" (Second Vatican Council, 1963/1992b #26). It is in this area and particularly in the worship aspect of liturgy that perhaps people with profound disabilities can lead the way. Pope John Paul draws attention to actual participation and especially to "active participation" in the liturgy, the experience that leads "to a deeper personal relationship with God" (1998, p. 4). The Pope develops active participation into "conscious participation." Pope John Paul is concerned here with the tendency in some thinking on the liturgy to make "the implicit explicit," to reduce or trivialize the act of worship or suppress "all subconscious experience" whereby "an affective and devotional vacuum is created" such that the liturgy risks becoming "not only too verbal but also too cerebral." For Pope John Paul, liturgy "feeds the heart and the mind, the body and the soul" (1998, #3). This is not to say that making the liturgy accessible is in any way to trivialize or cerebralize it. The point is that the profoundly disabled in their spiritual interiority, the level or extent of which cannot be grasped by others, offer a real witness to the work of God. This is precisely an area where people with profound disabilities can lead the way in an "active participation" that embraces "the active passivity of silence, stillness and listening" (1998, p. 3), spontaneous reactions, and in the "subconscious experience" that allows for the opening up to God as well as in a certain purity of heart. As the *Catechism of the Catholic Church* explains, "the preparation of hearts [to encounter the Lord] is the joint work of the Holy Spirit and the assembly" (Catechism of the Catholic Church, 1994, #1098). While signing the liturgy, providing visual and auditory signals are good practice in including the disabled, reducing their sense of isolation and fostering a sense of belonging, the realization that there are ways of being present and open to God that resemble perhaps the offering of an

emptiness to be filled can be a powerful reminder that spirituality is also God's work.

One of the ways in which the call to holiness is fostered is through the grace filled encounters with Jesus in the Sacraments. It is easy for the strong and autonomous to fall into the trap of seeing the call to holiness whether of the self or the other as primarily their own work, their own striving, and achievement. It is tempting to think of faith as principally a matter of increasing one's amount of religious knowledge, of knowing and learning more. Certainly inquiry, rational debate, and a thirst for knowing and understanding are important aspects of faith as is bringing the other to the doors of faith. However it is all too easy to lose sight of the fact that faith is about an encounter with Jesus. It is easy to neglect the dual dimension in the liturgy: That indeed there is a response of faith and love, but liturgy is not only about what we do; liturgy also conveys the spiritual blessings of the Father who is its source and goal. Christ acts and communicates his work of salvation through the liturgy and the sacraments. As the Catechism explains, "celebrated worthily in faith, the sacraments confer the grace that they signify. They are *efficacious* because in them Christ himself is at work" (Catechism of the Catholic Church, 1994, #1127) and "when the Spirit encounters in us the response of faith which he has aroused in us, he brings about genuine co-operation." (Catechism of the Catholic Church, 1994, #1091). And as St Augustine writes, "you were within me, you cried aloud to me, you broke the barrier of my deafness" (Augustine, c. 396AD/1994, X.27): God's grace can overcome physical and linguistic barriers.

Still, people with profound disabilities can give a further witness to the call to holiness and to become "participants of the divine nature." Written into the liturgy there is a place for bringing our needs, desires, and hopes before God. People with profound disabilities are often seen as the most needy, the *anawim*. Paradoxically they are unable or do not realize the extent of their apparent need in human terms. They just bring themselves in worship: It is a "here I am" of being. In doing so, they can give an example of the worship that is owed by all creatures: that of adoration of God from the nothingness of the creature who would not exist but for God.

SUMMARY

Both participation as "joining in" and participation as "being" engaged begin in encounter. Deep reflection and being with disabled people has led to a call to action, to inclusion, belonging and missing and to enabling participation as "joining in." Practice, reflection, thinking, act together to build up better understandings and in turn better practice, reflection, and thinking. Frequently, however, the more active human being does not realize that the other is engaged in this encounter: The other also participates by being and

in participating contributes. More often than not this is because the signs of engagement are not the usual ones or they are not obvious. However, just because participation and engagement are difficult to grasp does not mean to say that they are not taking place. Moreover, the participation involved at one of the most significant levels, that of participation in worship and liturgy and above all in holiness and the goal to become a friend of God is a participation that benefits from the witness of the contribution of "being" as well as doing. Taking an analogy with marriage, to be engaged is to be spoken for. "Being" engaged is participation in a relationship with God where the profoundly disabled person can be spoken for by the Spirit. It comes out of the "here I am" of simply being. That is a profound witness to all.

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